USAID

Health Technical Services Project

H T S

Discussion Papers on HIV/AIDS Care and Support

Systems for Delivering HIV/AIDS Care and Support

Prepared by
Helen Schietinger
Linda Sanei

Discussion Paper Number 8

June 1998

UNITED STATES AGENCY FOR INTERNATIONAL DEVELOPMENT

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Foreword

The U.S. Agency for International Development seeks to develop and promote effective strategies for providing basic care and support to those affected by HIV/AIDS. This series of Discussion Papers on HIV/AIDS Care and Support represents a first step in this effort.

HIV/AIDS care and support mitigate the effects of the pandemic on individuals, families, communities, and nations. Such interventions are an important component of the overall response to HIV/AIDS because they increase the impact of prevention strategies and mitigate the negative consequences of the epidemic on the prospects for sustainable development.

This series of Discussion Papers covers several key issues related to care and support:

\# Human rights and HIV/AIDS

\# Palliative care for HIV/AIDS in less developed countries

\# Preventing opportunistic infections in people infected with HIV

\# Psychosocial support for people living with HIV/AIDS

\# Community-based economic support for households affected by HIV/AIDS

\# Responding to the needs of children orphaned by HIV/AIDS

\# Systems for delivering HIV/AIDS care and support.

Each paper provides a preliminary review of some of the current thinking and research on these broad and complex topics. It is important to note that the papers are not meant to be comprehensive — time and resource constraints prevented the authors from reviewing all the relevant literature and from contacting all the people who have valuable experience in these and related fields. Nor have they been subject to technical or peer review. Their purpose is to stimulate a broad conversation on HIV/AIDS care that can help USAID define its future program activities in this area. We welcome your participation in this process.

Two additional papers on the topic of voluntary counseling and testing were prepared with USAID support:

\# The Cost Effectiveness of HIV Counseling and Testing

\# Voluntary HIV Counseling and Testing Efficacy Study: Final Report

These two papers are available from the IMPACT Project, Family Health International, 2101 Wilson Boulevard, Suite 700, Arlington, VA 22201; www.fhi.org.

Please direct your requests for copies of papers in the Discussion Series on HIV/AIDS Care and Support and your comments and suggestions on the issues they address to the Health Technical Services (HTS) Project, 1601 North Kent Street, Suite 1104, Arlington, VA 22209–2105; telephone (703) 516-9166; fax (703) 516-9188. Note that the papers can also be downloaded from the Internet at the HTS Project's web site (www.htsproject.com).

—Linda Sanei, Technical and Program Advisor,
Health Technical Services Project

Contents

Systems for Delivering HIV/AIDS Care and Support

Most programs in developing countries to provide care to people affected by HIV/AIDS have been initiated at the local level in response to local needs, but these community-based programs are being overwhelmed by the growing number of people living with HIV and AIDS who need care and support. Meeting this growing demand will require integrating such programs into the systems that deliver other types of health services (i.e., health care facilities and workplaces) and decentralizing them to adequately distribute resources to individual communities. Replicating successful community-based programs on a regional or national level will require technical assistance, expanded local capacity, and new and improved linkages and referral systems between health facilities and among such facilities and programs implemented outside the formal health sector. Such efforts should seek to ensure that all people have access to care, regardless of where they live or their socioeconomic status.

Programs to provide care to people affected by HIV/AIDS typically involve the entire range of care services addressed in the discussion papers in this series: human rights activities, palliative care, treatment for opportunistic infections, psychosocial support, socioeconomic support, and care for children affected by the epidemic. Many of these programs have been launched by the people who live in the communities hardest hit by HIV/AIDS in response to the suffering and hardship faced by their neighbors, friends, and family members. While these community-based programs are critical, they reach only a small percentage of the people in need, and

they face a chronic shortage of resources. Meeting the growing demand for support and care by people living with HIV and AIDS (PLWHAs) will require integrating such programs into the local and national systems through which people in these areas now receive other health care services. In addition, such programs will need to be decentralized to guarantee that resources are distributed to the local level to assist communities in continuing to respond to their particular needs.

The first section of this paper outlines how care is now being delivered in many communities affected by HIV/AIDS, including some characteristics shared by many care programs and some examples of typical programs. The second section addresses the challenge of scaling up current programs to create integrated systems of care and presents as models four programs that successfully expanded to the regional or the national level. The final section includes recommendations and a research agenda for further developing integrated systems of delivering care and support to people living with HIV/AIDS and their families.

CURRENT PROGRAMS TO DELIVER HIV/AIDS CARE

A notable feature of HIV/AIDS care programs is their similarity. Programs in countries around the world share a number of common characteristics, regardless of whether they are in industrialized or developing countries or in rural or urban settings. This seems more striking in light of the fact, mentioned above, that most care programs have been launched by the people in individual communities in response to their local needs. Below is an outline of some of the most common features of such programs.

Common Characteristics of HIV/AIDS Care Programs

The Integration of Prevention and Care Services
It is rare to find an HIV/AIDS care program that does not either have a prevention component or incorporate prevention into its care activities. The people who run such programs often have close relationships with their national AIDS control program and provide prevention literature and condoms to their clients.

Clients are typically counseled about strategies to prevent further transmission, including assistance in disclosing their HIV status to their sexual partners, referrals for the partners to obtain HIV counseling and testing, and information about initiating protective sexual behaviors within their relationships.

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Staff members and volunteers of programs that offer home-based care generally use a variety of informal opportunities to provide HIV/AIDS education to family members, particularly young people, during the course of their visits. They train caregivers to take appropriate precautions against contracting HIV through contact with infected blood. They often provide information about how HIV is *not* transmitted to allay the anxieties and fears of caregivers about the further spread of HIV within the household.

HIV/AIDS care programs also conduct many kinds of prevention activities in the community. The health care workers involved in such programs are often considered experts on AIDS prevention. They provide HIV/AIDS information and education in schools, through local civic and religious organizations, and to the media. In addition, the clients of AIDS care programs often become involved in outreach and prevention activities as a way to give something back to the community in return for the care they receive and to help others avoid becoming infected. Indeed, the willingness of people infected with HIV to publicly disclose their status is a vital aspect of prevention programs.

A Community-Based Response
HIV/AIDS care programs typically develop as a community response to the needs of people who are already affected by HIV/AIDS. The fact that they are community-based has been one of the strengths of such programs. Indeed, even those programs that are initiated within health facilities usually include activities that are based within the community, such as the provision of home-based services or delivery of services at a central location that members of the community can access on a walk-in basis.

Community-based programs provide reliable, accessible support to PLWHAs, allowing many to remain in their own homes. The local and neighborhood activities of such programs also help decrease the stigma associated with HIV/AIDS, which increases the likelihood that infected individuals will feel safe enough to disclose their status within their families and within the community. A study of decentralized services in a district in Botswana found that clients who were referred from a hospital to a health clinic nearer their homes had better follow-up care and a lower default rate than those whose care remained at the hospital level. Moreover, many of those who received home visits were counseled together with members of their families, because they were able to overcome their fears of stigmatization and breaches of confidentiality (Buwalda et al. 1994).

One disadvantage of community-based programs is that they provide only limited geographic coverage. For each community that has an active HIV/AIDS care program, there are many others that have none. People in communities that have no such programs, or that are beyond the range of the transportation system serving those that do, have little or no access to HIV/AIDS care services. This makes it important to replicate successful community-based programs on a regional or national basis (a challenge that is discussed in the second section of this paper).

Participation by People Living with HIV/AIDS
HIV/AIDS care programs generally depend on significant input and participation by people living with and affected by HIV/AIDS in planning and implementing their programs. In many cases, PLWHAs are the ones who launch such programs.

PLWHAs are particularly involved in peer support, community outreach, and advocacy activities related to HIV prevention, either as employees of the programs or as volunteers. When people feel safe about disclosing that they have HIV or AIDS and talk about the problems and needs of people like themselves, they can put a human face on HIV/AIDS for other members of their community and help reduce the stigma and discrimination that often surrounds HIV/AIDS.

PLWHAs are playing an increasingly important role in HIV/AIDS programming of all types and at all levels, local to international. As early as 1989, the World Health Organization's Global Programme on AIDS (WHO/GPA) had people living with and affected by HIV/AIDS on its global advisory body. The Joint United Nations Programme on AIDS (UNAIDS), which succeeded the GPA, has continued this tradition by including PLWHAs on its Co-ordinating Board (Kalibala, Rubaramira, and Kaleeba 1997).[1] National AIDS control programs promote the involvement of PLWHAs at the community level, where they are active in prevention projects; at the program level, where they participate on planning and advisory bodies; and at the national level, where they contribute to national policy and program discussions and decision-making, alongside representatives from government and nongovernmental organizations (NGOs).

The impact of PLWHAs "coming out" is profound, particularly in promoting the human rights of those affected by HIV/AIDS and in prevention activities. Personal experience is the single most effective tool in counteracting discrimination. People lose much of their prejudice against those infected with HIV when they personally

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[1]UNAIDS was established on January 1 1996, and coordinates the HIV/AIDS activities of five UN organizations (including WHO), and the World Bank.

interact with them. Likewise, personal experience is a powerful tool for promoting prevention. In countries around the world, people must see someone like themselves who has AIDS before they really believe that HIV/AIDS is a threat in their community. The more like themselves the person with HIV/AIDS, the more meaningful the encounter or experience. Videos of people from neighboring countries simply won't do. Men must see or meet a man; women must see or meet a woman.

Volunteerism

Many communities have mobilized to respond in caring ways to people living with HIV/AIDS, with community members offering both time and resources to improve the economic and psychosocial well-being of particularly hard-hit individuals and families. Volunteers are the backbone of HIV/AIDS care and support programs around the world, delivering care and prevention services and providing energy, enthusiasm, and commitment — and disproving those who expressed doubt that the type of volunteerism seen in many developed countries could be replicated in less developed countries.

In Zimbabwe, Red Cross volunteers provide home-care services to people with HIV/AIDS, who accept the support in part because the volunteers are from within their own communities. The volunteers receive two weeks of classroom training, two weeks of hospital training, and then work for two weeks under the supervision of trained home-care providers. After they complete their training, they are given a bicycle, a uniform, and a small expense allowance. They volunteer about four hours a day, three days a week. (AHRTAG 1995)

In the Victoria Project, implemented by a French NGO and the Lutheran Church, volunteers in Tanzanian villages near Lake Victoria take part in a community effort to care for vulnerable children. Each village elects a 16–member committee to identify needy children, discuss and establish priorities, maintain a register of orphans, and implement the activities. The volunteers provide needy children and families with food, clothing, bedding, and medical care, and pay for school fees, uniforms, books, and lunches. While the program could not function without its paid staff, it also could not function without the many volunteers who perform the daily tasks essential to ensuring that the children and families who are most needy receive services and supplies. (Mukoyogo and Williams 1991)

HIV/AIDS–Specific Services

HIV/AIDS care and support programs usually limit themselves to serving only people living with and affected by HIV/AIDS, in part because they are founded specifically to respond to needs that are not being met by existing organizations or agencies. HIV/AIDS programs generally do not broaden their objectives to serve people who are perceived to have other avenues of assistance, even if their health, socioeconomic, or human rights–related problems are similar to those of PLWAs. Many HIV/AIDS programs do, however, address the problems of people who are marginalized or otherwise alienated from mainstream society in ways that leave them more vulnerable to HIV transmission, such as commercial sex workers, out-of-school youth, and homosexual men.

The HIV/AIDS–specific nature of many programs enables the health care providers, staff members, and volunteers associated with them to build their expertise and increase their effectiveness in dealing with HIV/AIDS–related issues. For example, as counselors become more comfortable and experienced in dealing with the HIV counseling and testing process, they are more likely to deliver test results in a positive, supportive, and caring manner. Likewise, health care providers who are familiar with HIV/AIDS–related symptoms and diseases can more effectively diagnose and treat people — sometimes even without appropriate diagnostic technologies.

In addition, HIV/AIDS–specific programs can facilitate the coming together of people living with HIV/AIDS for mutual support. Particularly in communities with few people identified as having HIV/AIDS, the sense of isolation can be profound among people who are infected and affected, and support groups can play a particularly important and meaningful role in helping these people cope. It is often difficult to establish the first support group in a community, whether formal or informal, because people with HIV/AIDS fear being identified to others in the community, even to others who are infected.

One disadvantage of the HIV/AIDS–specific nature of the services (particularly the medical services) provided by many care programs is that they contribute to the impression that PLWHAs should be referred to specialty programs for treatment and care. This counteracts the impetus to integrate HIV/AIDS services with other health programs and services available at the community level. A result is that, especially in rural areas, people who cannot afford the time or the costs of traveling to a nearby AIDS clinic are deprived of care. Although the trend in developed countries is for HIV/AIDS care to be provided by specialists rather than generalists, this is largely because of the complexities of administering combination antiretroviral therapy. Given the absence of these drugs in the resource-constrained health systems of many

developing countries, however, a move toward specialized HIV/AIDS care, which is necessarily centralized, may simply deprive people of any care at the local level.

Another drawback to HIV/AIDS–specific clinics and home-care programs is that they may attract skilled health workers away from other vital community positions, exacerbating shortages of skilled health workers (Simon et al. 1991).

Dependence on External Funds

Another characteristic of HIV/AIDS care programs is their dependence upon external funding. Even AIDS clinics based in government-sponsored hospitals often receive external funding from private, sometimes religiously based private voluntary organizations (PVOs) and from bilateral or multilateral donor agencies. Care programs that are initiated within the community can sometimes survive solely on support from within the community, but usually in the form of donations; these programs are not generally self-funding either through fee-for-service payments or through subsidies from the broader health care system.

The most significant disadvantage of the dependence of care programs on grants and donations (of cash and in-kind resources) is the uncertainty of funding levels, which makes it difficult to plan future programs. Moreover, such funding is uneven and intermittent, resulting in alternating periods of abundance and scarcity of supplies and services. Uneven supplies of donated medicines can be particularly difficult to manage.

Provision of Comprehensive Services

HIV/AIDS care programs typically involve the provision or, at least, coordination of the entire range of care services discussed in the papers in this series:

\# human rights protection, including efforts to combat discrimination and stigma

\# palliative care services, including medical and nursing care and the services of traditional healers

\# psychosocial services, including emotional and spiritual support

\# socioeconomic services, including microenterprise services for income-generating activities and support for community-based assistance to impoverished families

\# care for affected children, including orphans.

Moreover, it is not unusual for those involved in HIV/AIDS care and support programs to be involved in efforts to shape policy and programming and to advocate for human rights protections at the local and national levels. Programs that cannot and do not offer particular services, such as medical care, usually attempt to establish linkages and referral systems with other service providers to ensure that their clients' needs are fully met. This is possible in part because staff members are generally well connected to other service agencies in the community.

The ability of community-based programs to meet the multiple and varied needs of their clients means that they often provide more integrated services than existing health care facilities or social service agencies. Even smaller, less sophisticated care programs may be better linked with community resources than large, well-funded public sector or quasi-public agencies. Building and improving the horizontal and vertical linkages among community-based organizations and government institutions will be vital to expanding the care and support available to PLWHAs. Such collaboration can yield important benefits:

> …it brings greater financial, material and human resources to bear on the problems, and helps to avoid duplication of effort; it facilitates the official acceptance and dissemination of innovative strategies and methods; it promotes a holistic approach, including the spiritual dimension of care and support, and it reduces the potential for mistrust, misunderstanding and rivalry. (Williams, Blibolo, and Kerouedan 1995)

Confidentiality
Respect for the confidentiality of people who are HIV–positive is a vital aspect of all HIV/AIDS care programs. The stigma associated with HIV makes it essential that programs have strong policies protecting information regarding the HIV status of clients, volunteers, and staff members. Many programs, including AIDS medical clinics, do not include "AIDS" or "HIV" in their names. Most hospital-based home-care programs do not display "AIDS" or "HIV" on their vehicles. Home-care workers never disclose a diagnosis to curious neighbors, or even to family members, without the express permission of their client. In fact, to reduce the problem of stigmatization and to maximize the use of resources, many AIDS–specific outreach projects have been more fully integrated into other community-based health care organizations (Osborne 1997).

Providing a safe and supportive environment in which PLWHAs can begin to disclose their status is important. Somewhat paradoxically, the guarantee of confidentiality gives many people the confidence to seek the type of care and support that can enable them to publicly disclose their HIV/AIDS status. It is critical that individuals never be coerced into disclosing their status and that they retain full control over any decision to "come out." According to the Association for AIDS-Affected Resource People (AAARP) in Zimbabwe:

> Individuals are being pressurized to give testimonies. Sometimes it feels as if the so-called experts are using people with HIV/AIDS as teaching aids. One of our major concerns is to prevent the abuse of [PLWHAs]. Our members can choose whether or not to reveal that they are HIV–positive. (Druce 1993)

Four Types of HIV/AIDS Care Programs

Programs that deliver HIV/AIDS care can be categorized according to their primary location: programs based within a community; programs based within healthcare facilities; programs based within the workplace; and programs based at the regional or national level that extend into a number of communities or healthcare facilities. The first three types are described briefly in this section, and the fourth is described in more detail in the following section on "Developing Integrated Systems of Care."

Programs Based in the Community
The strength of community-based programs is their roots deep within a particular locality, which inspires confidence among members of the community and gives those implementing the initiatives a clear, even intimate understanding of the needs and resources of the people they serve. Many community-based programs are developed by indigenous groups — women's groups, religious organizations, PLWHAs.

In some cases, such programs start with the vision of a single person. For instance, in Thailand, a charismatic traditional doctor who offered herbal remedies to PLWHAs and became known as the "Angel Doctor" for their renowned therapeutic effects, ignited a movement of PLWHAs who became vocal in demanding care. One woman organized the first response to the HIV/AIDS epidemic in Uganda by starting The AIDS Support Service Organization (TASO) in her home. TASO began as a grassroots self-help group but, with some external financial support, evolved into an

NGO offering a range of services in a number of areas, including a walk-in counseling center near the AIDS Clinic at Mulago Hospital in Kampala and basic home-care services to home-bound or bedridden AIDS patients in many communities. (Williams and Tamale 1991; World Bank 1997)

The World Bank has outlined four types of organizations that provide care and support services within their communities (World Bank 1997):

\# Client affinity groups: These may have the greatest credibility among people served by HIV/AIDS care programs because the staff members are typically drawn from and selected by those being served (World Bank 1997).

\# Social service clubs: These are local charitable organizations usually comprised of the middle and elite classes of society, the constituency to whom they are primarily accountable.

\# Non profit: These firms are beholden to an even smaller constituency, their boards of directors, but their numbers are growing substantially in some areas: "in the four years after the Brazilian government initiated a grant program for AIDS–related services, the number of NGOs registered with the Ministry of Health jumped from 120 to 480" (World Bank 1997).

\# Broad-based private charities, religious and secular: These charities typically represent a body of dues-paying members. An example is the Thai Red Cross Society, which organized the first HIV/AIDS support groups for affected individuals and their families in 1991 (World Bank 1997).

Women's organizations have been particularly important in initiating HIV/AIDS programs, particularly in India and Africa. WAMATA is a women's organization formed in Dar-es-Salaam in 1989 by a small group of women, led by Theresa Kaijaige.[2] The organization now has a dues-paying membership and also obtains support from the National AIDS Control Program, national organizations, and international donor agencies, including from USAID. Still, the bulk of its services are provided by volunteers at the community level, including HIV/AIDS community prevention and counseling; home visits to affected families to provide counseling and education, nursing care, and referrals to local medical facilities; support groups and income-generating activities for people with HIV/AIDS (Leonard 1994).

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[2]WAMATA stands for *Walio Katika Mapambano na AIDS Tanzania*, or People in the Fight against AIDS in Tanzania.

Many community-based services are sponsored by local spiritual communities. Churches and other religious organizations undertake service as part of their essential missions. They are particularly well suited to providing HIV/AIDS care:

> As organizations within the community they possess appropriate structures to reach people at the grassroots, to provide them with information and values involving respect for the values of others, to create and assist initiatives, to provide support where governmental activities are insufficient. (Fleischer 1993)

In Uganda, small Christian communities, or *kabondos,* provide support to neighboring families with HIV/AIDS. This support includes links to hospital-based or mobile home-based medical services; practical support such as preparing and cooking food, hauling water and firewood, cleaning house, and assisting with bathing; material support such as donated food, temporary housing, and revenues from income-generating projects; care and support of orphans; and emotional and spiritual support. In addition, the *kabondos* provide a role model for other community members by not shunning families affected by HIV/AIDS and working to diffuse neighbors' hostility toward or rejection of them. Another vital aspect of their community work is HIV prevention, which involves not only education about how to prevent HIV transmission, but also education and skills-training for women and youth, who become more vulnerable to HIV if economic necessity forces them to engage in commercial sex work or illegal drug trading (Williams and Tamale 1991).

Programs Based at Health Care Facilities

Many HIV/AIDS care programs are based within health care facilities but extend their services into the broader community. In particular, AIDS clinics gradually expand services to meet the multiple and growing needs of their HIV–positive clients to ultimately include home care. In addition, hospitals sometimes develop HIV/AIDS home care programs with the express purpose of facilitating the discharge of the large number of HIV/AIDS patients filling their beds.

Chulalongkorn Hospital in Bangkok, owned and operated by the Thai Red Cross, began providing care and support to people with HIV/AIDS and their families in 1985 — when many other hospitals in Thailand refused to care for those infected with HIV — with the opening of the Immune Clinic. The clinic quickly outgrew its quarters as a result of increasing demand. The clinic's staff of physicians, nurses, and social workers provides medical services and counseling services. In addition, the clinic

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offers support services provided by HIV–positive volunteers through the "Wednesday Friends Club." The club has been instrumental in fighting discrimination against people with HIV in Thailand. For example, it organized the first Candlelight March in 1991, which was presided over by Her Royal Highness Princess Soamsawali and attracted widespread media and public attention. The clinic's funding for staff and supplies is provided by the Thai Red Cross Society and the United Nations Children's Fund (UNICEF) (Sittitrai and Williams 1994).

Many hospital-based HIV/AIDS care programs are run by religious organizations, including the Reception Centre located at Dabou Protestant Hospital in Dabou, a town outside of Abidjan, Côte d'Ivoire. The first known cases of HIV infection were identified in 1987, when the hospital began to screen its blood supply. The Reception Centre was founded by a team of physicians, nurses, and religious leaders who quickly recognized the importance of providing support services in 1990, when the hospital attempted to notify individuals who tested positive for HIV infection and discovered the need "to help them cope with the psychological and social consequences of knowing their HIV status." They formed the "Support team for People with HIV and AIDS," and by 1991, they had obtained funding from Canada's international aid agency to build the Reception Centre to provide confidential counseling services and enable people with HIV/AIDS to meet with each other in private. The members of the team did not obtain formal training in HIV/AIDS counseling, communication, and education until 1992, after they had already begun to provide psychosocial support and opportunities for peer support in response to the expressed needs of their patients. The Support Team also began to visit patients in surrounding communities, using transport provided by the hospital's mobile team to provide primary health care in rural areas. (Williams, Blibolo, and Kerouedan 1995)

Outpatient and home-based care can be a valuable alternative to care in hospitals, but the cost-effectiveness of delivering such treatment through hospital-based programs should be examined more closely (Schopper and Walley 1992). For example, hospitals' outreach services are usually delivered in vehicles by professional staff members, which is costly compared to community-initiated home-care programs. Moreover, some of the services may be less effective than those offered by community-based home care programs:

> Mobile outreach programmes have a disadvantage that families and patients normally have to await scheduled visits and have no capacity to instigate visits according to need. Consequently, they may get no support at all when they most

> need it, and basic medication, both curative and palliative, may
> not be provided when required. (Osborne 1997)

Moreover, in resource-constrained settings, the home care provided by volunteers from within the community may actually provide basic and essential services to more people rather than highly technical services to fewer people, which is true of hospital-based programs.

Programs Based in the Workplace

Many large companies in developing countries run HIV/AIDS education programs for all employees and offer medical and psychosocial services to employees with HIV/AIDS and their families through onsite health clinics. Companies also provide pensions to disabled employees no longer able to work, assistance for burial costs, and time off for funerals and mourning.

Over 30 companies in Zimbabwe are running imaginative and effective work-based HIV/AIDS education programs, and other companies are providing medical care, social support, and education to employees and their families. For example, the National Railways of Zimbabwe offers care, support, and education programs at its 28 clinics throughout the country. The Eastern Highlands Tea Estate, among others, provides counseling, training, and free condoms. Red Cross volunteers from within the estate have begun home visits to people with AIDS to provide emotional support and train family members in basic home care. (ACTIONAID 1993)

The INDENI Petroleum Refinery Company, located in Zambia's Copperbelt Province, is one of 65 companies participating in an effort coordinated by the Ministry of Labour and Social Security to promote HIV/AIDS education and prevention in the workplace. INDENI provides prevention education and medical care and expends substantial amounts of money to provide paid sick leave to employees suffering with AIDS and to pay for deceased employees' funeral expenses. One important lesson from the workplace-based initiatives of the 65 companies involved in this initiative is that none has focused solely on HIV prevention; each has included some type of medical care and counseling. The companies believe this approach enhances the ability of HIV–positive individuals to come forward to seek the information and support they need to understand their condition and to live positive, responsible, and socially useful lives. (Leonard 1994)

Trade unions are also involved in HIV/AIDS care and support activities. The World Health Organization (WHO) and the International Labour Office (ILO) have developed guidelines on HIV/AIDS and the workplace. The most important role for

trade unions may be to lobby governments to enact legislation to protect HIV/AIDS–related rights in the workplace, particularly concerning such issues as HIV screening, confidentiality of medical information, medical insurance, and pensions for HIV–positive employees.

DEVELOPING INTEGRATED SYSTEMS OF CARE

The response from local communities around the globe to the needs of people living with HIV/AIDS has been both heroic and woefully insufficient:

> Many have been involved in hands-on activities to provide preventive education and care and support. Some people's actions are equivalent to using bare hands to stop a flood. Others have been told that what they are doing about the epidemic is too little compared to the problem and that it is unsustainable and makes no difference. In reply, these kind people say: "For the one I am doing it, it makes a life of a difference." Some have decided to use what they have today for the needs of those before them and have trusted that "tomorrow something will turn up." (Kalibala, Rubaramira, and Kaleeba 1997)

Although discrete HIV/AIDS care programs are critical local responses to the needs of PLWHAs and their families, overall they only reach a small percentage of people who are in need of support and care (Gilks 1997). Meeting the growing needs for care in most developing countries heavily impacted by HIV/AIDS will require replicating such programs many times over. This is happening in many areas, albeit slowly. For example, in Uganda, The AIDS Service Organization (TASO) is now working in at least six areas outside its original base in Kampala.

Even as these small local programs continue to serve their communities as best as they can and begin to be scaled up to provide a wider range of services to broader areas, the needs are growing faster. There is a role for governments to assist in extending the care and support now being provided.

In many countries, expanding HIV/AIDS care services through public sector health care facilities is difficult because of the heavy burden the epidemic has already placed on the limited resources and capabilities of such facilities. In a number of the countries in question, the vast majority of people receive health care either through the government-sponsored public health system or through facilities operated by NGOs,

including religious organizations. Private hospitals and employer-based health facilities serve only a small proportion of the population. Most government-sponsored primary health care systems deliver health care services through a system that begins with local primary care clinics, includes district-level facilities, and culminates in tertiary-care hospitals (although many such systems are being decentralized and, to a lesser extent, privatized). Most people are expected to obtain basic health care services at facilities within their communities, including perinatal care, vaccinations, and treatment for malaria, and to receive more complex services at district-level facilities and, if necessary, hospitals. In reality, however, community health facilities are often understaffed or underfunded, which leads people to bypass their local clinics, even for routine care, not least because a hospital pharmacy is more likely to have the medicine they need. The mid- and upper-level facilities are overutilized, and the local facilities are underutilized because they are under-funded and -staffed.

Many attribute the overall inadequacy of funding for health care — and the resulting mismanagement and shortages of staff, supplies, and medicines — to the fact that national governments place a low priority on health and welfare, as reflected in the national budget allocations for these sectors (WHO 1994). Others point to the impact of structural adjustment programs that have forced governments to cut back on health care expenses (Osborne 1997). Whatever the cause, the public health care sector faces significant constraints in most countries heavily impacted by HIV/AIDS. The poorest people in the countries are experiencing the greatest impact because they have little or no access to many essential health services.

The growing numbers of people with HIV place an immense burden on this system. Most HIV testing occurs in higher-level health care facilities, so patients are usually referred to these levels from local health centers if they are suspected of being HIV–positive. Because these facilities can be a long way from home for many people, a significant proportion do not make a second trip to obtain their test results. Even when they do, little effort is made to refer those who test positive for HIV back to their local health center for follow-up care because local facilities usually lack the expertise and medicines to provide such care. Indeed, so much of health providers' training has been in prevention (particularly, counseling and testing) that few providers have been trained to treat HIV–related symptoms and opportunistic infections, even within higher-level facilities. According to some reports, such ignorance may lead hospitals to test people for HIV and then simply to discharge them without telling them their diagnosis because of the belief that nothing can be done for them. The symptomatic treatment that is provided in such cases is often guided by generalists or by non–HIV specialists who do not recognize, much less attend to, other HIV–related clinical manifestations (Gilkes 1997).

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When people infected with HIV become ill, they seek health care services, regardless of whether they know their HIV status. As a result, the utilization of hospital care by people infected with HIV is rising, although many health care systems have little capacity to expand to meet that growing demand (Osborne 1997). In a study of six referral hospitals in developing countries with large epidemics, the percentage of beds occupied by HIV–positive patients ranged from 39 to 70 percent, with five of the six countries having 50 percent or more of hospital beds used by people with HIV infection (World Bank 1997).

Other research indicates that higher utilization of health care services by HIV–infected people is reducing access to medical care for people with other diseases. For example, in a Nairobi hospital, between 1988/89 and 1992, the average number of people admitted per day who were *not* infected with HIV went down by 18 percent, while the number of people who were infected more than doubled. The severity of the illness suffered by the non-HIV-infected patients also rose during that time, as evidenced by a jump in the mortality rate from 14 percent to 23 percent; in contrast, the mortality rate among the people with HIV infection who were hospitalized remained stable during that period. (World Bank 1997)

Within this context, specialized HIV/AIDS clinics and care programs are like oases in a desert of ever-expanding demand.

What is the answer? In order to provide all PLWHAs with access to health care, without overwhelming the health care system, HIV/AIDS–related services must be integrated with other health care services and decentralized to the local level, with appropriate drugs and treatment services available in local health clinics, enabling people to be cared for at home. This would provide access to HIV/AIDS care and support to the many families who can afford neither the time nor the cost of seeking care in higher-level facilities.

Clearly, one trend in health care at this point is toward decentralization. Health reform initiatives underway in a number of countries, such as Ghana and Zambia, have stimulated a decentralization of health services to the local level and spawned cost-recovery programs that may increase the local availability of drugs and services (Gilks 1997). Many national tuberculosis programs may be forced to use community-based health workers to supervise TB treatment because the current model,[3] which involves hospitalizing most patients for at least the first two months of therapy, is leaving

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[3]the health institution–linked Directly Observed Treatment, Short-course (DOTS) model

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hospitals overwhelmed by the number of new TB infections related to HIV (Raviglione 1997).

The syndromic management of HIV disease in adults and children is described in guidelines developed by WHO/GPA (WHO 1991). Many of the medications that are used to treat the symptoms and opportunistic infections related to HIV infection are common and inexpensive and are recommended for inclusion on all countries' essential drug lists (WHO 1995). Moreover, when used prophylactically, these same drugs can extend the lives of many people living with HIV.[4] However, these medications are often unavailable, particularly in smaller, more remote areas — exactly where they could reach the people most in need. Also, as noted, few health care providers have been trained to diagnose and treat HIV–related disease.

Only those models of care should be expanded that provide the most cost-effective and appropriate services and that strengthen and maximize the efficient use of existing health infrastructures. When health care is then linked to other community-based services, the HIV/AIDS Prevention and Care Continuum — the matrix of interrelated services that complement and support each other — is completed.
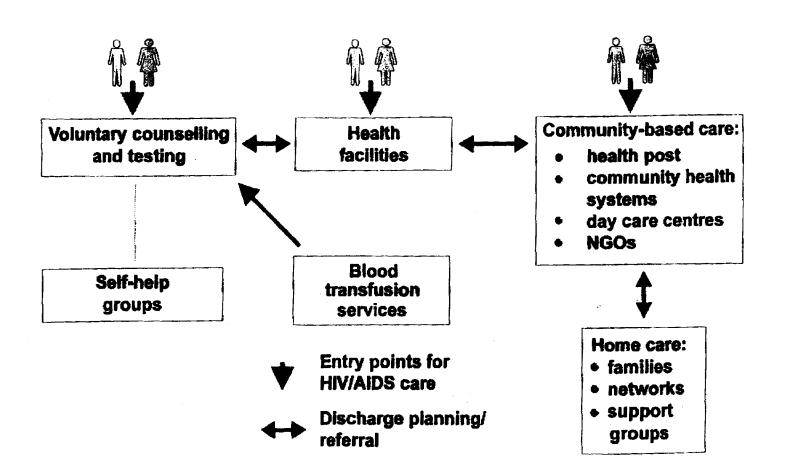
A Continuum of HIV/AIDS Prevention and Care

A paradigm for this scenario was developed at an international meeting of experts on "Provision of HIV/AIDS Care in Resource-Constrained Settings," held in September 1994 by WHO. The deliberations form an excellent basis for the enormous task of health reform and are outlined below and illustrated in Figure 1 (WHO 1994).

Equity of access to good-quality care: Health care must be denied no one because of their HIV status and must be accessible to all people, whether they live in rural or urban areas, are female or male, or can afford to pay fees or not. Minimum acceptable standards should be developed for counseling, medical and nursing care, and monitoring and evaluation of proposed services. The special needs of women and children with HIV must be recognized.

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[4]See the discussion papers in this series on treatment of opportunistic infections and on palliative care: Kaplan et al. (1996/1998) and Sanei (1998).

Figure 1. The World Health Organization's HIV/AIDS Continuum of Care

\#   Care across the full spectrum of HIV–related diseases: People with HIV infection fall sick and need care at all stages of the disease; AIDS is only the final and most apparent stage. Early associated infections, such as pneumonia, tuberculosis, and septicaemia, are relatively easy to diagnose, and they respond well to treatment. Some of these conditions are public health priorities in their own right, including TB. Home-care programs for PLWHAs could provide an important means of early detection of TB and supervising adherence to treatments. Treatment protocols should follow nationally established guidelines and involve essential drugs.

\#   Better utilization of appropriate levels of health care services: All levels within the health care system must provide appropriate services to prevent overutilization of higher-level facilities (i.e., hospitals). This requires an effective referral system and discharge planning for HIV–infected people. Improving the quality of services provided at all levels can make facilities more effective in providing the types of care that people will utilize. For HIV/AIDS–related services this involves having adequate supplies and medications, using appropriate guidelines, ensuring adequate training for effective HIV/AIDS care, and promoting a nondiscriminatory attitude among staff members toward those who are HIV–positive. In some cases, major health policy and system reforms will be needed.

\#   Support and improvement of existing community services: HIV/AIDS–affected families need special attention. This requires that the community-based services they use should be based on up-to-date knowledge, positive attitudes, and commitment. Effective community initiatives must be supported, encouraged, and linked to appropriate health care providers that can provide complementary and comprehensive support. NGOs involved in these community approaches should be recognized and supported.

\#   Improved coordination of existing services: Careful coordination is needed within and among services provided to people with HIV/AIDS for TB, maternal and child health, and prevention and treatment of sexually transmitted infections (STIs) to reduce duplication and inappropriate use of services. This should include the integration of services generally perceived to be separate, such as health and social support services. Such integration is necessary at all levels, and leadership should come from national governments during health care reform and decentralization activities.

\#   New initiatives for care: Particular importance should be given to networking and referral systems, self-help and support groups for PLWHAs, care for orphans, voluntary counseling and testing, palliative care, traditional healers,

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and reproductive health in HIV–positive women. Providers of care in the private and business sectors should be encouraged to develop complementary initiatives in partnership with governments and NGOs.

\# Human resources development and capacity-building: The capacity to provide high-quality health care depends on effective and committed management. Medium-term plans for HIV/AIDS care need to incorporate appropriate training and supervision at all levels in the health care system and encompass all relevant groups. Adequate updating of materials and retraining/refresher training must be included in training programs. Positive attitudes and commitment must be promoted among health care providers.

\# Enhancing the capacity of communities to support their members: Communities have an innate capacity to respond to the needs of their members, but this capacity is often overwhelmed and eroded by excessive demands. In some places, extensive community resources exist but go untapped. Methods must be explored for strengthening existing social support systems to enhance communities' ability to cope and for mobilizing and supporting communities to devise sustainable responses based on local needs and resources.

Models of National or Regional Programs

As noted, community-based HIV/AIDS care and support programs are unique and often highly effective responses to the particular needs of an individual community. Such effective responses are needed in much larger areas and by many more people than can be served by existing programs (WHO 1994).

Governments can help mitigate the impact of the HIV/AIDS pandemic by "scaling up" such effective community-based programs or by developing national programs with the resources and capacity to disseminate some level of HIV health services to all communities. Ultimately, in order for care programs to be sustainable, governments and communities must be able to pay the total cost of such programs. Even when communities or NGOs initiate and fund national or regional programs, governments have an important role to play in conducting HIV surveillance, evaluating the costs and effectiveness of various interventions, introducing and enforcing supportive workplace and human rights legislation, ensuring access to treatment for the most vulnerable populations, and promoting labor-intensive economic growth to reduce poverty. Most countries have established national AIDS control programs, which incorporate many of these roles.

This section reviews four programs that have extended beyond single communities and represent models for the type of expanded, integrated HIV/AIDS prevention and care systems that are needed. Each of the programs provides only limited services, although all reach large numbers of people, which underscores the need for strong linkages with other local programs to ensure comprehensive care across the continuum of need.

ZINATHA (Zimbabwe)

The partnership between ZINATHA (Zimbabwe National Traditional Healers Association) and the Zimbabwe Ministry of Health (MOH) mobilizes traditional healers for community-based HIV/AIDS prevention and care.[5] The program was initiated in part because the first Minister of Health of the independent Zimbabwe was both a medical doctor and a traditional header, and he recognized the value of traditional practices.

One unique aspect of the ZINATHA program is its work with chiefs and other opinion leaders to encourage modification of some traditional practices that actually encourage the spread of HIV/AIDS, such as scarification and inheritance/cleansing of widows by male relatives. Another unique element is the series of national workshops sponsored by the MOH to inform healers about HIV/AIDS and to help define their role in HIV/AIDS prevention and care. The workshops cover modes of HIV transmission, symptoms and diagnosis of AIDS, and counseling and care of people infected with HIV.

The project seeks to mobilize community-based health providers to conduct home visits. "Some healers report that they have been able to persuade families to care for AIDS patients by explaining to them that to do otherwise would contradict traditional values and provoke the displeasure of the ancestors." The government is also investigating the effectiveness of traditional treatments, in part because of its interest in legitimizing the potential contribution of traditional medicine to the fight against AIDS. Specifically, two wards of Zimbabwe's largest public hospital offer the patients an option to have their AIDS–related illnesses treated by traditional medical practitioners, and ZINATHA encourages healers to register to participate in clinical trials, which are carried out under the auspices of the MOH. ZINATHA's operating budget comes from annual membership subscriptions.

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[5]This description of ZINATHA was drawn from Leonard (1995), and quoted passages refer to this document.

Rwanda Red Cross Project Info-SIDA
In 1991, the Rwanda Red Cross AIDS Education Project (Project Info-SIDA) developed a program to train its Red Cross volunteers to teach families how to provide basic nursing care to sick family members, with the objective of providing support to families caring for people with HIV/AIDS in villages remote from health care facilities throughout the country (Schietinger et al. 1993). The volunteers, who were already recognized as AIDS educators in their communities, underwent five days of training to teach basic nursing skills, provided by a nurse based in the Red Cross Society's national office who remained in touch with them monthly by mail after they returned to their villages. The volunteers were given a small handbook in Kinyarwanda, the national language, that described symptom management for common HIV–related symptoms.[6]

The volunteers made home visits to families in their villages to teach them such skills as how to bathe the sick person in bed and how to prevent dehydration. Although the volunteers avoided offering to visit only those families affected by HIV/AIDS because of the potential stigma for their clients, many of families were indeed living with HIV/AIDS and confided in the volunteers because they were known as AIDS educators in the community. This is typical of HIV/AIDS home-based care programs, which have a much wider client base when families are able to maintain confidentiality from the community unless and until they are ready to disclose that their family member has HIV/AIDS (Kalibala, Rubaramira, and Kaleeba 1997; Druce 1993).

An evaluation of the program found that although the volunteers made home visits because they felt they had skills to offer, they wished that they had some tangible items to bring, such as food or paracetamol, because the families were usually so poor. On the other hand, the families highly valued the visits themselves, particularly the encouragement they received from the volunteers. The fact that the intervention was simple and not formally linked with the health care system meant that it could be implemented with minimal resources and replicated widely.

Community-Based Counseling Program (Uganda)
In 1991, the Uganda Ministry of Health (MOH) began a pilot project of the Community-Based Counseling Program which mobilizes community volunteers to

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[6] This was the field test of *Caring for People with AIDS at Home,* a booklet later published in English by the International Federation of Red Cross and Red Crescent Societies (IFRC 1993).

carry out HIV/AIDS prevention education and counseling and to support people with HIV/AIDS in their homes (Leonard 1994). Two districts outside the city of Kampala were selected.

Community counseling aides (CCAs) were selected to represent villages in each district and were provided with a 30-day training in HIV counseling, HIV prevention, and basic nursing care. Under the supervision of the District Health Team, the CCAs provide supportive counseling to people discharged from the hospital, refer people to health clinics for HIV testing, and then keep in touch with them after they return home. Some people do not admit to the CCAs that they have AIDS because of a fear of stigmatization, but they still receive home visits during which the CCA can provide HIV–prevention counseling to them and their families. In addition to family counseling, the CCAs serve as educational resources for the entire community, speaking to groups and working with district trainers and health care providers to conduct HIV/AIDS education and outreach projects.

An evaluation of the program found that not only did the CCAs generate tremendous community involvement, but that they were highly motivated volunteers despite the fact that they received no compensation for the large amounts of time they devoted to their activities. The MOH feels that the success of the program in the two districts hinges in part on the constant involvement and supervision in the field by the District Health Team.

Compared to the Rwanda Red Cross program, this program provides more intensive training and supervisory involvement with the volunteers in the field and more concrete linkages with the health care system. On the other hand, the MOH is unable to continue to provide support on an ongoing basis because of the costs. The MOH will train trainers at the district level in new districts, but they will begin to encourage district administrations to solicit support from existing local organizations to oversee ongoing project activities. Thus, the MOH has not been able to establish a plan to sustain the effort on an ongoing basis, which further reinforces the need for strong linkages between government and NGO programs.

Community-Based Options for Protection and Empowerment (Malawi)
In 1995, Save The Children/US launched an orphans support program in Malawi entitled the Community-Based Options for Protection and Empowerment (COPE), with funding from USAID. Piloted in one district, the program has multiple health, socioeconomic, and psychosocial objectives, but its main intervention is to provide training for people who care for sick family members and for community volunteers (Williamson and Donahue 1996). The training includes how to treat

common ailments and how to help patients stay comfortable and retain their dignity. It also encourages caregivers to build their own support systems among family members and neighbors to help with labor, food, and other needs. Moreover, the staff trains volunteers as trainers and builds village-level networks of caregivers and trained volunteers, through which participants can support each other and share resources, information, and skills. Religious leaders and village leaders also are trained. Thus, the program generates community-based support for families.

This home-based level of palliative care is of great benefit in a country in which the health care system does not have the resources to provide counseling and HIV testing throughout the health care system, much less to treat opportunistic infections:

> Once doctors … have determined that an AIDS patient or otherwise terminally ill person will not benefit significantly from continuing hospital care, the patient is told that there is nothing more that can be done and then sent home without a diagnosis. (Hunter and Donahue 1997)

Home-based care has been recognized as needed and important within communities, and has had a substantial "multiplier effect."

COPE's intervention is coordinated with other interventions that seek to maintain families' incomes when an adult is ill and to provide a supportive family and community environment for orphans being cared for by families in the community. The wide range of programs is staff-intensive and costly, and a recent evaluation determined that the program should be revised in order to be sustainable and replicable on a larger scale, even within the district. Thus, further attention needs to be given to how programs such as this can be implemented on a national level. According to the evaluation report:

> Approaches are needed that can be taken to scale. Interventions to address problems among children and families affected by HIV/AIDS should be developed and carried out with a perspective not only on the needs of the immediate community, but also considering the overall scope of the problems in the country. (Hunter and Donahue 1997)

RECOMMENDATIONS

\# Provide technical assistance and capacity-building in rational pharmaceutical management, including facilitation of policy dialogue regarding drugs for pain management and treatment of opportunistic infections to be included on essential drug lists.

\# Promote resource allocation within the health budgets of countries to provide sufficient drugs, supplies, and staff at the district and local levels of the primary care system to diagnose and treat HIV–related disease.

\# Provide training and capacity-building to enable health care providers in district and local health centers to provide HIV counseling and testing, prophylaxis, and treatment for specific opportunistic infections, and to monitor people with HIV/AIDS throughout the course of the disease.

\# Integrate HIV/AIDS care into existing systems for providing maternal and child health care, preventing and treating sexually transmitted infections, and controlling and treating tuberculosis, and promote utilization of peripheral levels of the health system.

\# Establish and improve linkages and referral between the levels of the health system and between the health system and community-based services. Improve coordination of services, particularly between institutional and community-based services.

\# Assure equity in access to health care for all people with HIV/AIDS, regardless of socioeconomic status or area of residence.

Research Agenda

\# Conduct operational research to compare various models of community-based care in relation to quality and scope of services, cost-effectiveness, and impact on quality of life.

\# Conduct operational research to evaluate the effectiveness of integrating HIV/AIDS care into existing systems of care, establishing linkages among all sectors involved in providing HIV–related services, and utilizing volunteer support at the community level to deliver services.

\# Determine the characteristics of referral systems and community-based services that enhance the optimal use of health care services.

\# Conduct operational research on the feasibility, cost, and sustainability of interventions that enhance the capacity of communities to provide support.

\# Evaluate the effect of integrating HIV/AIDS care into primary care and decentralizing HIV/AIDS care on the quality of life of people with HIV/AIDS and their families.

\# Conduct operational research on the feasibility, cost, and sustainability of integrating HIV/AIDS care into primary care, decentralizing primary care, and strengthening essential drug programs.

Annex A: References

ACTIONAID. 1993. *Work Against AIDS,* Strategies for Hope Series No. 8. London: ACTIONAID.

AHRTAG. 1995. *AIDS Action*. London: Appropriate Health Resrouces Technologies Action Group, Ltd. (March-May).

Buwalda, P., D. J. Kruijthoff, M. DeBruyn, and A. Hogewoning. 1994. "Evaluation of a Home-Care/Counseling AIDS Programme in Kgatleng District, Botswana," *AIDS Care* 6(2):153–60.

Druce, N. 1993. *AIDS Action Newsletter,* No. 16. London: Appropriate Health Resources and Technologies Action Group (AHRTAG).

Fleischer, K. 1993. "Special Problems in the "Third World" — Possibilities of Interventions Concerning Prevention and Care of AIDS in the Third World," *Tropical Medicine and Parasitology 44,* special issue on the Second Conference of the International Ethical Committee on AIDS.

Gilks, C., E. Katabira, and K. M. DeCock. 1997. "The Challenge of Providing Effective Care for HIV/AIDS in Africa," *AIDS* 11 (Suppl B): S99–S106.

Hunter, S., and J. Donahue. 1997. *HIV/AIDS Orphans and NGOs in Zambia: Strategy Development for Programming by the USAID/Zambia Mission for Family and Community Care of Children Affected by HIV/AIDS.* Washington, DC: TvT Associates for USAID Mission to Zambia, Lusaka (June).

IFRC. 1993. *Caring for People with AIDS at Home.* Geneva: International Federation of Red Cross and Red Crescent Societies (November).

Kalibala, S., R. Rubaramira, and N. Kaleeba. 1997. "Non-Governmental Organizations and Community Responses to HIV/AIDS and the Role of HIV-Positive Persons in Prevention and Care, *AIDS* 11(Suppl B):S151–57.

Kaplan, J. E., D. J. Hu, K. Holmes, H. W. Jaffe, H. Masur, and K. M. DeCock. 1996/1998. "Preventing Opportunistic Infections in Human Immunodeficiency Virus–Infected Persons: Implications for the Developing World," *American

Journal of Tropical Medicine and Hygiene 55(1). Reprinted with permission as Discussion Paper on HIV/AIDS Care No. 4. Arlington, VA: Health Technical Services (HTS) Project (June).

Leonard, A., ed. 1994. *Community-Based AIDS Prevention and Care in Africa: Building on Local Initiatives.* New York: Population Council.

Mukoyogo, M. C., and G. Williams. 1991. *AIDS Orphans: A Community Perspective from Tanzania,* Strategies for Hope No. 5. London: ACTIONAID (June).

Osborne, C. M., E. van Praag, and H. Jackson. 1997. "Models of Care for Patients with HIV/AIDS," *AIDS* 11 (Suppl B): S99–S106.

Raviglione, M. C., A. D. Harries, R. Msiska, D. Wilkinson, and P. Nunn. 1997. "Tuberculosis and HIV: Current Status in Africa," *AIDS* 11 (Suppl B): S115–23.

Sanei, L. 1998. *Palliative Care for HIV/AIDS in Resource-Poor Settings,* Discussion Paper on HIV/AIDS Care No. 3. Arlington, VA: Health Technical Services (HTS) Project (June).

Schietinger, H., C. Almedal, N. M. Bizimungu, K. J. Ruruku, and B. L. Ravn. 1993. "Teaching Rwandan Families to Care for People with AIDS at Home," *The Hospice Journal* 9(1):33–53.

Simon, J., E. Ratsma, E. P. Manjolo, and J. Trostle. 1991. *Voices from the Epidemic: AReport of the Needs Assessment for Community/Home Care in Malawi,* unpublished report. Cambridge, MA: Harvard Institute for International Development (December 31).

Sittitrai, W., and G. Williams. 1994. *Candles of Hope: The AIDS Programme of the Thai Red Cross Society,* Strategies for Hope Series No. 9 London: ACTIONAID (July).

WHO. 1991. *Guidelines for the Clinical Management of HIV Infection in Adults.* Geneva: World Health Organization Global Programme on AIDS, UN Document No. WHO/GPA/IDS/HCS/91.6 (December).

———. 1994. *Provision of HIV/AIDS Care in Resource-Constrained Settings.* Geneva: World Health Organization Global Programme on AIDS, UN Document No. WHO/GPA/TCO/HCS/95.14 (September).

———. 1995. *WHO Model Prescribing Information. Drugs Used in STDs and HIV Infection.* Geneva: World Health Organization.

Williams, G., A. D. Blibolo, and K. Kerouedan. 1995. *Filling the Gaps: Care and Support for People with HIV/AIDS in Cote d'Ivoire,* Strategies for Hope Series No. 10. London: ACTIONAID (November).

Williams, G., and N. Tamale. 1991. *The Caring Community: Coping with AIDS in Urban Uganda,* Strategies for Hope Series No. 6. London: ACTIONAID (November).

Williamson, J., and J. Donahue. 1996. *Developing Interventions to Benefit Children and Families Affected by HIV/AIDS: A Mid-Term Review of the COPE (Community-Based Options for Protection and Empowerment] Project of Save the Children USA in Malawi.* Washington, DC: TvT Associates for the Displaced Children and Orphans Fund, USAID (October).

World Bank. 1997. *Confronting AIDS: Public Priorities in a Global Epidemic.* Policy Research Report. New York: Oxford University Press.

Annex B: Acronyms

Below is a list of the acronyms used in this report.

AAARP	Association for AIDS-Affected Resource People (Zimbabwe)
CBO	Community-based organization
CCA	Community counseling aides
COPE	Community-Based Options for Protection and Empowerment
GPA	Global Programme on AIDS (WHO)
HIV/AIDS	Human immunodeficiency virus/acquired immunodeficiency syndrome
HTS	Health Technical Services Project
ILO	International Labour Organization
MOH	Ministry of Health
NGO	Nongovernmental organization
PLWHA	Person/people living with HIV and AIDS
Project Info-SIDA	Rwanda Red Cross AIDS Education Project
PVO	Private voluntary organization
STI	Sexually transmitted infection
TASO	The AIDS Support Service Organization (Uganda)
UNAIDS	Joint United Nations Programme on AIDS
UNDP	United Nations Development Programme
USAID	United States Agency for International Development
WAMATA	*Walio Katika Mapambano na AIDS Tanzania* (People in the Fight against AIDS in Tanzania)

WHO   World Health Organization

ZINATHA   Zimbabwe National Traditional Healers Association

Annex C: Prevention and Care Dynamic of Systems for Delivering HIV/AIDS Care and Support

Figure 2. Prevention and Care Dynamic of Systems for Delivering HIV/AIDS Care and Support				
Intervention	**Immediate Beneficiary**	**Primary Benefit**	**Mitigating Effect**	**Prevention Benefit**
Rational pharmaceutical management to ensure drugs for pain and symptom management and prophylaxis and treatment of opportunistic infections, including TB at local health facilities	People living with HIV/AIDS and their families	More PLWHAs have access to appropriate treatment	Families are protected from exposure to active TB; PLWHAs are able to remain productive longer	More people have access to appropriate treatment for sexually transmitted infections (STIs), which reduces HIV transmission
Strengthening primary health care at the local level to ensure palliative care	People living with HIV/AIDS and their families	More PLWHAs and their families have access to health care	Improve general health of PLWHAs and their families	More people are reached with STI treatments, reducing HIV transmission
Expanding and replicating community-based HIV/AIDS services with home-care components	People living with HIV/AIDS and their families	Improves quality of life for PLWHAs	Reduces stress level of families affected by HIV/AIDS	Affected families and broader community receive HIV/AIDS prevention education

Figure 2. Prevention and Care Dynamic of Systems for Delivering HIV/AIDS Care and Support				
Intervention	**Immediate Beneficiary**	**Primary Benefit**	**Mitigating Effect**	**Prevention Benefit**
Build and improve linkages and referral systems among HIV/AIDS service organizations and other services, including TB control and primary health care	People living with HIV/AIDS	Comprehensive care is provided	Improves health of PLWHAs by ensuring access to a wider range of care services for HIV/AIDS–related illnesses	Family and community receive HIV prevention education